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ABSTRACT

Some of the problems facing parents of handicapped children are considered, and the importance of families planning for the future of their children with chronic disabilities is stressed. In addition to the problems encountered by parents who raise non-handicapped children, parents of a handicapped child must cope with community rejection, stereotyping, and restricted educational and service opportunities. In view of today's improved medical technology and longer life expectancies for handicapped persons, many parents are delaying or simply stalling about making arrangements for their child following their death. Counseling to assist parents in making future plans for their children is suggested. (SW)

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PARENT AND FAMILY ATTITUDES TOWARD LONG-TERM PLANNING

by

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Parent and Family Attitudes Toward Long-term Planning

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J. Larry Tyler, James W. Mann, and Don L. Frugé*

Normal parenthood has many joys, sorrows, and rewards. The presence of a handicapped child in a family elicits many of these same emotions, but many additional feelings as well. Having a handicapped child is no special "badge of distinction," actively sought by most families. Parenthood is difficult enough without the added demands and responsibilities of caring for a dependent child.

Have you ever met a parent who said he desired to have a handicapped child? I doubt it. Well, then, who's having all the exceptional children enrolled in state and private programs? Is it only those individuals trapped in a cycle of poverty, the undereducated, and those with restricted life options? Or, is it just possible that your next-door neighbor has a child with Down's Syndrome? A friend at the office with a cerebral palsied child? An aunt or uncle with a child who you have heard was in an institution somewhere? The answer may include any one of these. Obviously, none of us is immune from the developmental quirks of nature. Further, none of us is immune from the shock and trauma experienced when told that serious problems developed during delivery and that our infant has been placed in a "high-risk" category. Who, for example, is adequately prepared to witness first-hand developmental anomalies in a long-awaited child? I submit it is more common that you think. Mental retardation and other handicapping conditions rank among the nation's most serious health, social, and economic problems. Only four disabling conditions have a higher incidence rate: cancer, arthritis, cardiac disease, and mental illness (Walthall and Love, 1974).

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Let's examine these parents and families a little closer. You may think that parents of handicapped children are more "special" than you or I. Are they? Were they singled out in some divine way to bear the pain of raising an exceptional child? Are their psyches, motivations, personality characteristics, habits, and traits any different from yours and mine? For years researchers have looked at parent characteristics to describe this unique segment of our population. Issues studied include: How do education or income levels affect a family's ability to integrate a defective child into the home or community structure? Are protestant families more accepting than Catholic or Jewish families? What differences appear among various racial/ethnic groups regarding child acceptance and family integration? These questions and multitudes of others provide interesting reading and study for those counseling families of handicapped children. If you want to see a good cross section of America, just attend a few national parent conferences, such as the National Association for Retarded Citizens, United Cerebral Palsy, or the Association for Children with Learning Disabilities. Indeed, they are your neighbors, your friends, your relatives, or, possibly, even you!

The birth of a defective child immediately throws up a red flag to some parents. They may think: Should we request that medical treatment be withheld, or should extra precautions be taken to preserve life? Should we plan to keep the child at home or plan for an institution? What are the genetic risks for other children? The questions are endless. Since most parents plan for a normal pregnancy and a healthy child, little thought is given to these issues prior to birth--except in cases of certain prenatal diagnoses. Only after the child's arrival with its associated difficulties do parents get serious about coping strategies and ways of meeting the child's needs.

How difficult is it in the 1980s to be the parent of a handicapped child? What problems do they encounter that are unique to their situation--that are outside the normal routines of most parents? Someone has said that while it is "easy to parent, it is more difficult to be a parent." These are more than just "glib" words for those who face the daily grind of caring for a severely handicapped child or adult. The literature is full of parent difficulties: high medical bills, lack of sitting services, lack of home aides, nursing services, and respite services, restricted travel, little time for leisure, and coping with hard-to-manage behaviors. Dunlap and Hollingsworth (1977) studied

400 rural, low-income families with a developmentally disabled family member. Among the difficulties they noted included securing day care, baby sitting and homemaker services, self-care training, financial assistance, and education. Other problems included seizure control and problems occurring at vacation or shopping time.

On a larger scale, families of developmentally disabled clients face a myriad of problems within society at large. These include:

1) hostile attitudes and unacceptance within society (even though progressive gains have been made in the 1960s and 1970s);
2) community rejection;
3) obstacles to community living;
4) restrictive zoning ordinances;
5) antagonistic forces for social change;
6) employment barriers; fewer job opportunities;
7) state and federal obstacles in monetary/fiscal policies;
8) stereotyping by diagnostic/classification labels; role expectations;
9) obstacles in voter participation, marriage, and community living;
10) lack of citizen and legal advocacy;
11) restricted educational and service opportunities, particularly above age 21.

On these issues, Schulman (1980) alluded to the "but" factor by stating: "Too many 'buts' are curbing the implementation of social change for retarded persons. . . . still prejudices ferment good intentions, and the status quo reigns supreme because administrators can usually discover a 'but' that erases many changes (p. 401)."

The chronicity of life-long mental retardation makes it a difficult condition to deal with at best. Persons experienced in counseling families with handicapped children are quite familiar with the various stages of emotional development experienced by parents once a definitive diagnosis is made. The areas of guilt, ambivalence, frustration, anger, shame, rejection, sorrow, embarrassment, denial, bereavement, and chronic sorrow have been well researched (Schild, 1976; Wolfensberger, 1967). But what about parents' plans for the future? What are their hopes, aspirations, goals, expectations, and future plans? Schulman (1980) has observed that with "better medical technology and longer life expectations for handicapped persons, parents are simply delaying or stalling about making arrangements for their child following their death."

White (1972) writes that for most parents, making future plans for their child is an issue that "creates consternation and procrastination." Obviously, many factors are involved in a family's planning or lack of it. Factors such as level of income, education, degree of social acceptance, family integration and stability, number of siblings, and family attitudes are all important. Still, the best intentions often are sidetracked due to parent inertia, procrastination, unconcern, or an unwillingness to face the ultimate decision that a time will come when they will no longer be able to make decisions and provide the needed services and security required by their child.

In order to assist parents in decision making for the future, the NARC has published a pamphlet, How to Provide for Their Future (1978) that discusses guardianship, wills, trusts, general estate planning, insurance benefits, and general governmental benefits for retarded adults. Families often need assistance and guidance regarding property arrangements and the establishment of trusts. Other members of the panel will speak to those issues today. Other valuable publications of assistance to parents include the booklet, Now . . . and the Future, available from the South Carolina DD Council, and two publications through the Research and Training Center for the Handicapped at the University of Mississippi: (1) Estate Planning for Retarded Persons and Their Families (Frugè and Green), and (2) Planning a More Secure Future for Your Developmentally Disabled Family Member. The NARC pamphlet provides the following information:

> You have many factors to consider in providing lifetime protection for your retarded children. You should consider obtaining a judicial determination of mental incompetence shortly before the age of 18. You should consider the advisability of the appointment of a guardian for anyone found to be legally incompetent.
>
> It is vital that you prepare a will upon the advice of a competent attorney. Your will may create a trust that will make proper financial provision for all of your children, including your retarded child, or you may create a living trust before you die.
>
> Life insurance on your life is essential. The proceeds from it can enlarge your estate or trust and increase the protection of your children. In planning both your life insurance and your total estate, you will want not to forget the benefits available to your survivors under the Social Security Act and the other governmental programs described here.
>
> Keep in mind that the various factors affecting your future plans for your retarded child are related and must be considered in an entire, overall single picture.
>
> Plan now to avoid future complications and heartache. Review and revise your plans periodically.

Families need adequate counseling not only in the medical/genetic/developmental areas, but in making life-long decisions about their child. Not only must the counselor/helper be competent in his field, but he must be an empathic listener and accurate observer of parent motivations and desires. Certainly the financial and housing arrangements needed are important in planning, but making sure that the necessary community support services are available is equally important. Another issue to be faced surrounds the skill mastery or developmental level of the child or adult. After the parents are gone, is he/she capable of independent living? Are companion services needed or a guardianship arrangement required? Preparing adequate resources early can ease parents' anxieties and make their ultimate demise less traumatic for all concerned.

How do we get parents concerned about making future plans for their child? Much has been written about parent advocacy in the areas of prevention, early detection, service delivery patterns, policy making, and the need for community programs. But what about advocacy programs to sensitize parents to their need for secure future planning? Is future planning less important since it occurs later in the child's life, generally? I don't think so. Since parents react differently to their child's handicap, it is difficult to generalize about the type of parent who plans and those who don't. MacKeth (1973) points out that parents' reactions to handicapped children vary according to the time of onset, the severity, the apparentness of the condition, and their perception of the degree of community stigma. Further, one could assume that parents' receptivity to comprehensive planning is influenced by a host of personal, emotional, or economic factors.

Finally, the idea of designing long-range plans to care for a handicapped child poses some interesting questions regarding social policy and practice--especially if our health care policies are not static and are destined to change and evolve over time. For example, on either a philosophical or pragmatic level one might ask: Do parents have the right to be relieved of extended child-rearing functions as they approach advancing years or if their son or daughter is already an adult? Have we reached the pinnacle in providing adequate social provisions to handicapped children and their families, or are new models of service required for those instances where normal family gratifications are thwarted in order to provide for a severely handicapped child? Schild (1976)

asserts that more planning and development of community living facilities for the adult handicapped are needed "so that the normal processes of parent-child emancipation can be possible (p. 464)."

These issues aside, it behooves those of us in the helping disciplines to devise techniques that will assist parents in the planning process. By using the resources of CEC, parent organizations, lay and professional groups, the print and television media, governmental agencies, information referral sources, University Affiliated Programs, and last of all, personal contact, an effort should be made to provide accurate, reliable information to parents about future planning. As Schulman (1980) writes:

> Preparing for the inevitable death of parents is eased if adequate resources are established early enough. The risk, rights, and responsibilities of growing up as parents of retarded persons are complex but have the potential for providing many satisfactions and opportunities for peoplemaking (p. 125).

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